

## Complete Summary

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### GUIDELINE TITLE

National statement of good practice for the treatment and care of people who have epilepsy.

### BIBLIOGRAPHIC SOURCE(S)

Frost S, Crawford P, Mera S, Chappell B. National statement of good practice for the treatment and care of people who have epilepsy. Liverpool (UK): Joint Epilepsy Council; 2002 Mar. 20 p. [51 references]

### GUIDELINE STATUS

This is the current release of the guideline.

## COMPLETE SUMMARY CONTENT

SCOPE  
 METHODOLOGY - including Rating Scheme and Cost Analysis  
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 INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT  
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## SCOPE

### DISEASE/CONDITION(S)

Epilepsy

### GUIDELINE CATEGORY

Counseling  
 Diagnosis  
 Management  
 Treatment

### CLINICAL SPECIALTY

Family Practice  
 Internal Medicine

Neurological Surgery  
Neurology  
Psychiatry

## INTENDED USERS

Advanced Practice Nurses  
Nurses  
Occupational Therapists  
Physician Assistants  
Physicians  
Psychologists/Non-physician Behavioral Health Clinicians  
Social Workers

## GUIDELINE OBJECTIVE(S)

- To provide a series of recommendations for attaining high quality National Health Service care for people with epilepsy
- To improve the clinical management of epilepsy with particular emphasis on the role of integrated care
- To recognise the importance of, and to improve, social and psychological management
- To improve the medium- and long-term quality of life for those with epilepsy, whether seizure-free or not
- To increase the number of people who successfully withdraw from therapy
- To outline the multidisciplinary team that is required to provide quality epilepsy services
- To describe how general practice should contribute to quality epilepsy care
- To improve the professional development of people who work in the epilepsy field
- To improve epilepsy services through review and reflection

## TARGET POPULATION

Individuals with epilepsy

## INTERVENTIONS AND PRACTICES CONSIDERED

1. Integrated epilepsy care
2. Communication of a diagnostic decision
3. Early follow-up including supporting systems
4. Antiepileptic drugs (AEDs)
5. Addressing social and psychological issues
6. Information and education for individuals with epilepsy and their families
7. Nonpharmaceutical treatment including neurosurgery, vagal nerve stimulation, and complimentary therapies in combination with AEDs
8. Gradual withdrawal of AEDs

## MAJOR OUTCOMES CONSIDERED

- Rate of epilepsy misdiagnosis

- Efficacy of antiepileptic drugs and their adverse event profiles

## METHODOLOGY

### METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)  
Hand-searches of Published Literature (Secondary Sources)  
Searches of Electronic Databases

### DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

In preparing this National Statement, the Clinical Standards Advisory Group Report (CSAG) and Scottish Intercollegiate Guidelines Network (SIGN) documents were initially consulted, both of which had a thorough literature search strategy of their own. Further MEDLINE searches were carried out and standard textbooks and other important reports (e.g., Epilepsy Task Force Survey) were also consulted.

### NUMBER OF SOURCE DOCUMENTS

Not stated

### METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

### RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

### METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review

### DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

### METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

### DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

## RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

## COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

## METHOD OF GUIDELINE VALIDATION

Comparison with Guidelines from Other Groups

## DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

In preparing this National Statement, the Clinical Standards Advisory Group Report (CSAG) and Scottish Intercollegiate Guidelines Network (SIGN) documents were consulted.

## RECOMMENDATIONS

### MAJOR RECOMMENDATIONS

Definitions for the type of supporting evidence are provided at the end of the "Major Recommendations" field.

#### Immediate Care

##### Aims

- To improve the clinical management of epilepsy with particular emphasis on the role of integrated care
- To recognise the importance of, and to improve, social and psychological management

##### Standards

##### A. Integrated Epilepsy Care

- a. All people experiencing seizures should have rapid access to diagnostic services and appropriate treatment (Brown et al., 1998; Clinical Standards Advisory Group [CSAG], 1999). GRADE P
- b. Planned integrated care covering general practice and specialist epilepsy services is the preferred model of care (Epilepsy Working Group, 1995; CSAG, 1999). GRADE C2
- c. A Patient Held Record where all parties recognise their role should be developed for each person. This plan should address the clinical, social, and psychological needs of the individual. Copies of this plan should be held by all concerned, including the person with epilepsy or their guardian. GRADE P & U

## B. Diagnosis

- a. All service users presenting with a first seizure should be seen within 28 days of referral (Brown et al., 1993; Epilepsy Task Force, 1998; Epilepsy Advisory Board, 2000) to a specialist with an interest in epilepsy. GRADE P & U
- b. Specialist services should be encouraged to organise first seizure clinics, where investigations and consultation/s can take place on the same day. GRADE P
- c. The misdiagnosis rate for epilepsy has been estimated to be around 20 to 30% (Scheepers, Clough, & Pickles, 1998; Wallace et al., 1997; GRADE P); therefore all pertinent information should be collected and extreme care taken before making a diagnosis. The medical history and eyewitness accounts are still the most important pieces of information (Scottish Intercollegiate Guidelines Network [SIGN], 1997; Taylor, 2000). GRADE B3
- d. A level three diagnosis (e.g., a syndromic diagnosis) should be made wherever possible. If not, level two should be attained (e.g., seizure type/s). A diagnosis of simply epilepsy is very rarely, if ever, justified (SIGN, 1997). GRADE P

## C. Investigations

All appropriate investigations need to be conveniently available within 28 days (Brown et al, 1998; Epilepsy Advisory Board, 2000). This will help the physician to make decisions quickly and safely, especially concerning the initial diagnosis. Investigatory delays that consequently delay clinical decisions are unacceptable. GRADE P & U

## D. Nonepileptic Seizures

Nonepileptic seizures are more common than once thought (King et al., 1982). All staff of each service should be sensitive to the potential diagnosis of nonepileptic seizures and, where appropriate, be able to contribute towards their diagnosis. There are few staff in England that specialise in this area of care. Relevant referral needs to be considered, if and when local knowledge is insufficient. GRADE P

## E. Communicating a Diagnostic Decision

An individual's feelings on receiving a diagnosis of epilepsy should be respected. Communicating the diagnostic decision appropriately is arguably as important as making the initial decision itself. Individuals need to be informed fully about their diagnosis and its potential implications (Cooper and Huitson, 1986; Risdale et al, 1996; Wallace et al., 1997); therefore adequate time should always be allowed for reaction and questions. Privacy is essential. Where needed, access should be provided to other sources of support (Risdale et al., 1996; SIGN, 1997; Wallace et al., 1997; Brown et al., 1998; Epilepsy Task Force, 1998). GRADE P & U

## F. Early Follow-up

- a. Support systems should be in place to provide help and information within 7 days of diagnosis. All service users should be able to access

relevant follow up with a professional who has the required experience. GRADE P & U

- b. This should provide both opportunity for the service user to ask questions about their concerns and for the professional to confirm the facts and issues raised by the diagnosis. GRADE P & U

#### G. Starting Treatment

- a. People should not be treated if there is uncertainty about the diagnosis (SIGN, 1997). Inappropriate treatment can worsen seizure disorders (Parker et al., 1998). GRADE C1
- b. It should not be assumed that everyone diagnosed with epilepsy will want treatment. This matter should always be explored, as noncompliance with prescribed therapies is a major issue (Stanaway, Lambie, & Johnson, 1985). How treatment works should always be explained. GRADE B3
- c. Unlike other diagnoses, people with a certain diagnosis of unprovoked generalised tonic-clonic seizures should be offered treatment after the first seizure, if the seizures are associated with previous myoclonic and/or absence seizures ("Randomized clinical trial," 1993). GRADE A1
- d. The decision to treat other seizure types may depend on the seizure frequency and severity (SIGN, 1997). GRADE P
- e. Seizures arising from alcohol withdrawal and other metabolic or drug-related causes or sleep deprivation should not routinely be treated with antiepileptic drugs [AEDs]. Treatment may be considered if there are recurrences suggestive of epilepsy (SIGN, 1997). GRADE P
- f. All people developing seizures as a consequence of head injury should be treated, but drug withdrawal should be subsequently considered (SIGN, 1997). GRADE P

#### H. Antiepileptic drugs (AEDs)

AEDs are the first line treatment for epilepsy. There is now additional choice in the range of AEDs. Principally the choice of AED should be based on the most appropriate for the person's seizure type/s and syndrome, their age and sex (Taylor, 2000). Associated consideration should be given to potential adverse effects. There is now a wide variance in the cost of AEDs (British Medical Association, 2001.) Where there is clear evidence that an individual will benefit from a more expensive AED, this should not be denied due to budgetary constraints. Although there is no evidence to suggest that one AED is generally more efficacious than any other, there is evidence (Heller et al., 1995; Richens et al., 1994; Turnbull et al., 1985; Mattson et al., 1985; Mattson, Cramer, & Collins, 1992) that some are more efficacious for certain seizure types and syndromes. There is evidence that some have better adverse event profiles (Richens et al., 1994; Mattson, Cramer, & Collins, 1992; Brodie, Richens, & Yuen, 1995). GRADE A1

#### I. Potential Social and Psychological Issues

##### Common Social Issues

Many people with epilepsy rate social implications as a major problem (Taylor, 2000; Collings, 1994). Where the law allows, suggestions should be made as

to how people can safely partake or participate in the normal range of social activities. GRADE C1

### Common Psychological Issues

Epilepsy has psychological implications for some people (CSAG, 1999; Jacoby et al., 1996). This should be at the forefront of the service provider's agenda. A positive attitude communicated by the service provider can be very helpful. More common topics that require addressing are, "felt and enacted" stigma, stress, mood changes (including depression), and family and other relationships. GRADE B3

## J. Information and Education Needs of Individuals and Their Family

### What and When?

- a. The information needs of people with epilepsy and their family are diverse in terms of content and relevance to the individual, and the timing of provision. The following checklist is offered as an aide-memoire to ensure that needs are fully explored, if and when relevant:

Epilepsy Information	Antiepileptic Drug (AED) Information	Seizure Triggers	Lifestyle Implications
Aetiology Classification Epidemiology Prognosis Inheritance SUDEP* Seizure diary  *Sudden unexplained death in epilepsy	AED regimen Side effects Compliance Missed doses Free prescriptions Drug interactions Withdrawal	Lack of sleep Alcohol withdrawal Stress Illness Reflex stimuli	Driving Work Education Leisure Safety Contraception Preconception Parenting
Psychological Implications	First Aid	Voluntary Organisations	
Felt and enacted stigma Stress Mood changes Family relationships Other relationships Anxiety Depression	Complex partial seizures Tonic-clonic seizures Status epilepticus	Contact details and information about services provided by voluntary organizations is available from the Joint Epilepsy Council, c/o Mersey Region Epilepsy Association, Glaxo Neurological Centre, Norton Street, Liverpool L3 8LR	

(Adopted from SIGN, 1997; Epilepsy Association of Scotland "Epilepsy Checklist" [cited in Taylor, 2000]; CSAG, 1999) GRADE C1

### Continuing Care

#### Aim

- To improve the medium- and long-term quality of life for those with epilepsy, whether seizure free or not

#### Standards

##### A. On-going Care

Planned integrated care spanning general practice and specialist epilepsy services should continue (Epilepsy Working Group, 1995; CSAG, 1999).  
GRADE C2

The Patient Held Record where all parties recognise their role should continue.  
GRADE P

##### B. Specific Areas of Care

###### a. Diagnosis

If seizures are continuing the diagnosis should be reviewed and other differential diagnoses ruled out (SIGN, 1997; Epilepsy Task Force, 1998; Scheepers, Clough, & Pickles, 1998). GRADE B3

###### b. Investigations

Where relevant, rapid access should be available to further pertinent investigations. These may be new investigations or repeats of previous in an attempt to find new information concerning causation, syndrome, or any other relevant reason. GRADE P

###### c. AEDs

Where the first choice or choices of AEDs have been unsuccessful, the specialist team should carefully consider other alternative monotherapy or reasoned polytherapy (Heller et al., 1995; Richens et al., 1994; Turnbull et al., 1985; Mattson et al., 1985; Mattson, Cramer, & Collins, 1992) GRADE A1

###### d. Nonpharmaceutical Treatment

###### I. Neurosurgery

All services should provide access to neurosurgery as there is a significant group of people who do not respond satisfactorily to AEDs who will benefit from neurosurgery if selected correctly (Wieser, 1998). GRADE A2



Services should purchase neurosurgical services from specialist centres.

Certain cases of lesional epilepsy may be directly amenable to neurosurgical treatment after suitable work up. Neurosurgery should be considered in ALL client groups after two years of unsuccessful AED treatment (SIGN, 1997; Taylor, 2000; Wallace et al., 1997; CSAG, 1999). GRADE P

## II. Vagal Nerve Stimulation

Vagal nerve stimulation may be a useful treatment for some individuals. GRADE B1. It is a treatment option that should be considered at a similar time to neurosurgical options (Schachter and Saper, 1998). GRADE P

## III. Complementary (Alternative) Therapies

There is no data to support the use of complementary therapies instead of AEDs, but there is data to suggest (Betts, 1995) that used in combination with AEDs (complementary) they may benefit some people (Taylor, 2000). This is especially so in those with associated anxiety and depression (Boden, Betts, & Clouston, 1990). GRADE D

## e. Social and Psychological Care

Professionals should avoid concentrating on clinical issues if the individual's agenda is different. It is likely that social and psychological issues will be high on the individual's agenda at differing times (CSAG, 1999; British Epilepsy Association [BEA], 2000). GRADE C1.

Individuals should be referred to appropriate information and support services (Epilepsy Advisory Board, 2000; Wallace et al., 1997). GRADE B3

## f. Information Needs

Continuing information and education needs of individuals and their family may vary dependent on the clinical, social, and psychological outcome of early care. Continuing care should recognise the importance of accurate information (SIGN, 1997; Cooper and Huitson, 1986; Jain, Patterson, & Morrow, 1993; Risdale et al., 1996). GRADE P

## Remission

### Aim

- To increase the number of people who successfully withdraw from therapy

### Standards

#### A. Making a Decision

Withdrawal of medication is possible under certain circumstances, as it has been shown that twenty years from diagnosis approximately 50% of people will be seizure free and off medication (Annegers, Hauser, & Elveback, 1979). Deciding when remission actually occurs is difficult, but it is sensible to discuss withdrawal after two years seizure free ("Randomised study," 1991 - GRADE B1; Taylor, 2000). A decision to start withdrawal of therapy should consider all relevant factors and importantly involve the complete cooperation of the individual (SIGN, 1997; Taylor, 2000).

#### B. Discussing the Potential Risks and Implications

A recurrence of one seizure may have massive implications (for employment, education, driving etc.); therefore each individual should be fully informed through extensive discussion and information provision (Taylor, 2000; SIGN, 1997). GRADE P

#### C. Withdrawing therapies

All AEDs should be withdrawn gradually (Taylor, 2000), especially the barbiturates and benzodiazepines (Berg, Shinnar, & Chadwick, 1997). GRADE A2

### Special Service Requirements and the Role of General Practice

#### Aims

- To outline the multidisciplinary team that is required to provide quality epilepsy services
- To describe how general practice should contribute to quality epilepsy care

#### Standards

##### A. Specialist Epilepsy Services (within integrated care)

- a. Dependent on the group of service users, the lead physician should be a consultant with a specialist interest and experience in epilepsy from a relevant speciality (Epilepsy Task Force, 1998; CSAG, 1999; Epilepsy Advisory Board, 2000). GRADE P & U

NB: "A particular interest in epilepsy" requires substantial experience in the treatment and care of a wide range of people with epilepsy plus a commitment to ongoing professional education.

- b. Integrated epilepsy care should also include the following:

- I. Swift access to appropriate neurophysiology and neuroimaging services (e.g., magnetic resonance imaging [MRI] and video-telemetry)
- II. Specialist epilepsy nursing
- III. Well developed links to other professional services (e.g., appropriate in-patient facilities, psychology, psychiatry, social

- work, occupational therapy, counselling, neurosurgical services [traditional, vagal nerve stimulation, and gamma knife] and complementary therapists)
- IV. Access to information, support, and other services from the voluntary sector (Brown et al., 1998; CSAG, 1999). GRADE P & U

- c. Some people may require access to the following additional services:
- I. Clinical psychology (especially for neurosurgical assessment).
  - II. Research services (i.e., new therapies in development) (Brown et al., 1998). GRADE P

#### B. The Role of General Practice (within integrated care)

General practice has a vital role in the management of epilepsy, especially in the coordination of care with particular emphasis on social, psychological, and emotional support.

General practice should provide:

- a. A comprehensive standard protocol for referral that helps to secure an accurate diagnosis
- b. Access to the best available specialist epilepsy service within reasonable traveling distance
- c. Support pre and post the diagnosis of epilepsy
- d. Guidance about accessing information by using resources such as specialist nurses, local and national voluntary organisations
- e. Prescription and adjustment of AEDs should be recorded in the individual's Patient Held Record.
- f. Regular review of individuals on a practice register dependent on severity and changing circumstances. This should be at least annually for all.
- g. Rereferral to specialist services when appropriate (i.e., poor control of seizures, adverse events, withdrawal of AEDs, preconception etc.) (Taylor, 2000; CSAG, 1999). GRADE C2

#### Education and Monitoring

##### Aims

- To improve the professional development of people who work in the epilepsy field
- To improve epilepsy services through review and reflection

##### Standards

- A. Staff within the "Specialist Service" should show a commitment to ongoing professional education in epilepsy. A recognised qualification in epilepsy and membership of an appropriate professional body is desirable (e.g., International League Against Epilepsy [ILAE] or Epilepsy Specialist Nurses Association [ESNA]). GRADE P & U

Refer to the original guideline document for information on monitoring epilepsy services.

#### Definitions:

##### Evidence from Research and Other Professional Literature

A1 Systematic reviews which include at least one Randomised Control Trial (RCT) (e.g., Systematic Reviews from Cochrane or Reviews and Dissemination)

A2 Other systematic and high quality reviews which synthesise references

B1 Individual RCTs

B2 Individual nonrandomised, experimental/intervention studies

B3 Individual well-designed nonexperimental studies, controlled statistically if appropriate; includes studies using case control, longitudinal, cohort, matched pairs, or cross-sectional random sample methodologies, and well-designed qualitative studies; well-designed analytical studies including secondary analysis

C1 Descriptive and other research or evaluation not in B (e.g., convenience samples)

C2 Case studies and examples of good practice

D Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified

##### Evidence from Expert Opinion

P Professional opinion based on clinical evidence, or reports of committees

U User opinion from Service Users Reference Group or similar

C Carers opinion from Carers Focus Group or similar

##### CLINICAL ALGORITHM(S)

An algorithm is provided for Epilepsy Care Pathway.

#### EVIDENCE SUPPORTING THE RECOMMENDATIONS

##### REFERENCES SUPPORTING THE RECOMMENDATIONS

[References open in a new window](#)

##### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified for each recommendation (see "Major Recommendations")

## BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

### POTENTIAL BENEFITS

- Improved clinical management of epilepsy with particular emphasis on the role of integrated care
- Improved social and psychological management
- Improved medium- and long-term quality of life for those with epilepsy
- Increased number of people who successfully withdraw from therapy
- Overall improved quality of epilepsy care including general practice and specialist care

### POTENTIAL HARMS

Not stated

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

### IMPLEMENTATION TOOLS

Clinical Algorithm

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

Getting Better  
Living with Illness

### IOM DOMAIN

Effectiveness  
Patient-centeredness

## IDENTIFYING INFORMATION AND AVAILABILITY

### BIBLIOGRAPHIC SOURCE(S)

Frost S, Crawford P, Mera S, Chappell B. National statement of good practice for the treatment and care of people who have epilepsy. Liverpool (UK): Joint Epilepsy Council; 2002 Mar. 20 p. [51 references]

#### ADAPTATION

Not applicable: The guideline was not adapted from another source.

#### DATE RELEASED

2002 Mar

#### GUIDELINE DEVELOPER(S)

Joint Epilepsy Council - Disease Specific Society

#### SOURCE(S) OF FUNDING

Joint Epilepsy Council

#### GUIDELINE COMMITTEE

Not stated

#### COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Research Team: Sarah Frost; Brian Chappell; Professor Pamela Crawford; Dr Stephen Mera

Steering Group Members: Professor Stephen Brown (Chair); Sue Thomas; Pat Noons; Dr David McCormick; Jim Oates; Mike Harnor; Dr Ley Sander; Dr Keith Redhead; Peter Rogan (JEC); Julie Tickle; Hilary Mountfield

#### FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

#### GUIDELINE STATUS

This is the current release of the guideline.

#### GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the [Joint Epilepsy Council Web site](#).

Print copies: Available from the Joint Epilepsy Council c/o Mersey Region Epilepsy Association, Glaxo Neurological Centre, Norton St, Liverpool L3 8LR.

#### AVAILABILITY OF COMPANION DOCUMENTS

None available

## PATIENT RESOURCES

None available

## NGC STATUS

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Date Modified: 10/9/2006

